

The HALI Project's Medical Home Model

Our Company Overview

The HALI Project is a tax-exempt, 501 (c) (3) organization established in 1999 by Brad and Karen Thompson in response to the challenges they were (and still are) facing in raising their daughter Hali. With the help of a tremendous group of partners, we forged the HALI Project and established a Mission Statement which is *to inspire people with special needs and their families to dream new dreams through teaching and encouragement; and to improve the quality of care these families receive by providing support to those who serve them.*

Our Vision for the HALI Project and the people it serves has not changed since the beginning. We want to be a leading, positive force in facilitating the full, appropriate inclusion of individuals with special needs, including people with developmental disabilities, in their communities. We know that when all members have the opportunity to contribute their gifts, communities are better for it. We see our role as playing a part to help achieve that goal.

Mission Statement

To inspire people with special needs and their families to dream new dreams through teaching and encouragement; to improve the quality of care these families receive by providing support to those who serve them.

Vision Statement

Improve the quality of life for people with special needs, their families, and the people who are involved in their care and development.

Goals

1. Provide ongoing comprehensive and coordinated care for families, resulting in improved health outcomes and quality of life for all people, but especially individuals with special needs.
2. Enhance the operational efficiency of primary care practices' provision of coordinated and comprehensive care by training *parent partners* to provide support in the "non-medical" areas of the medical home model as defined by the American Academy of Pediatrics..
3. Improve access to families of children with special needs to the organizations and professional medical societies trying to serve them.
4. Improve the profitability of companies linked to pediatric care; not just the ones like us working to improve efficiencies and optimize delivery of chronic care but also those companies who are involved in health insurance and home health care and, indeed, the Federal Government itself.

Importance of Goals & Barriers

1. Provide ongoing comprehensive and coordinated care for families, resulting in improved health outcomes for the children.

1. Raise recognition to the fact that a child with special needs faces not only medical challenges, but also educational, social, and family challenges. Having a parent partner that can address those needs before, during, or after a doctor's visit can improve the overall well-being of the child and the family and contribute to better outcomes.
2. Families often have difficulty navigating the medical system, as well as mental health, health insurance, social service, education, housing, and other services to meet a wide array of complex needs. The HALI Project can educate and train parent partners to facilitate smooth navigation of this tough terrain.
3. Enhance the operational efficiency of primary care practices' provision of coordinated and comprehensive care by training parent partners to provide support in the "non-medical" areas of the medical home model.

An experienced parent partner can provide resources for families that reach beyond the medical practice's scope, streamlining a provider's daily activities.

Primary care providers face the daily challenge of maintaining a crowded schedule with meeting the needs and concerns that each family brings to an exam room. Many times these questions fall outside of the provider's expertise, but his/her compassion for the family leads to a search for the answers, taking valuable time that is not reimbursable.

4. Research indicates that parents who receive support from other parents are better able to adjust to their child's disability and have better attitudes, increased coping abilities, and greater progress in solving problems.
5. Pediatric primary and specialty care providers report that lack of time, reimbursement, knowledge about resources, and experience prevent them from adequately guiding these families and linking them to existing services. These barriers often preclude practitioners from providing such children with a medical home that offers family-centered, comprehensive, coordinated, and integrated care.

2. Improve access to families of children with special needs for the organizations trying to serve them.

1. Publicly supported organizations have taken on the task of providing support for families of children with special needs, but due to privacy and confidentiality issues, they lack direct access to those families. This fact complicates their ability to reach and serve these families.
2. Partnering with a primary care office addresses that challenge by making it as convenient as possible for families to connect to these organizations.

3. Improve the profitability of companies linked to pediatric care. Insurance companies – both public and private - probably have the most to gain from improving the quality of medical homes across the country. Multiple studies have supported the idea that primary/preventive care is the most efficient use of medical resources, yet many families use the emergency room – the least efficient use of medical resources – as their primary source of care. Providing higher quality coordinated and comprehensive care (with the parent partner playing an integral role in that) has shown to reduce overall healthcare costs (see the Rhode Island PPEP project).

Current Status of the Project

Our Medical Home project began very simply. Dr. Shari Medford – a pediatrician and a mother of a child with special needs in Amarillo, TX – had grown frustrated by the number of times she had passed along The HALI Project's phone number to parents of children with special needs, only to find out that they rarely made the call. Our mutual desire to serve these families eventually led to a partnership that consisted of Dr Medford scheduling well-child visits for children with special needs on Fridays, and Brad Thompson spending that day at her office, meeting these families as they waited for their appointments. That was in 2004. Since then, we have been blessed to meet and help 100's of families in Dr. Medford's practice. While Dr. Medford addressed the medical needs of the child, Brad would talk with the parents about a broad range of subjects from school issues to available resources.

In 2010, The HALI Project brought its model to Nebraska and partnered with The Boys Town Institute for Child Health Improvement to develop a program combining pieces of the Rhode Island Pediatric Practice Enhancement Project (PPEP) to build the capacity of medical homes in Nebraska. Through this pilot program, five pediatric practices in Nebraska have been chosen to house a Professional Parent Coordinator so they can serve as the "hub" for coordination of health services and family supports in the community, as well as assure that all services are fully integrated into the primary preventive health care model.

On a small scale to this point, we have seen this program address many of the concerns reported by pediatricians when it comes to serving children with special healthcare needs. Having a parent consultant available frees them of the responsibility of searching for resources outside of the medical community. It also allows the pediatrician to connect their parents to another parent who has both the time and the practical experience of being on this journey as well to support them along the way. This support may begin during an office visit but in many cases will lead to

support relationships that spread beyond the medical arena to school, resources, and community support opportunities.

As word has spread in the communities that our consultants are working, they are being seen as “community resources” by others who work with our families. Several of our consultants have received referrals from other pediatricians in their community as well as other agencies. I believe this is important for two reasons. First, most family support groups lack any opportunity for direct contact. They depend on a referral which is rarely followed up on for multiple reasons, not the least of which is a “To Do” list that is already too long. Second, in a time of increasingly tight budgets, the opportunity to partner with multiple local groups can produce greater results with fewer dollars.

There are multiple benefits to the practice. First, the pediatrician is allowed to focus on his/her area of expertise – medicine – while providing the family with a high quality resource to meet the family’s other needs of relationship, support, and resources. The presence of the parent consultant frees the doctor to see more patients by reducing the amount of time spent with each patient while adding to the quality of the visit for the family. This impact can improve the doctor’s “bottom line” by spending more time providing services that are reimbursable. We believe it can also improve the doctor’s quality of life by allowing them the opportunity to go home earlier if they so choose. In our Nebraska practices, our consultants are also focusing on the “no shows” in the practice. We believe that contact from a parent encouraging the follow-through on an appointment will have a greater impact on a parent (especially another mom) than a computerized message or even a live call from office personnel. By increasing the efficiency of staff time and lowering the “no show” rate, we believe that our consultants will begin to pay for themselves within the first year of their work.

In September 2012, we entered into a partnership with the Mountain States Genetics Regional Collaborative and the Wyoming Health Department to begin a project working in three practices. Training for the partners will begin in January 2013 and their work in the practices will begin immediately thereafter.

The Model

Research indicates that parents who receive support from other parents are better able to adjust to their child’s disability and have better attitudes, increased coping abilities, and greater problem solving ability. The Hali Project Medical Home Model trains parent partners to serve as the “hub” in primary care practices for coordination of health services and family supports in the community, as well as assure that all services are fully integrated into the primary preventive health care model.

The model begins with a parent who is involved in the process because of his/her experience in raising their own children with their own children with special needs. These parents can understand the realities and frustrations and can offer both empathy and practical advice. Because our partners are local, they’ve had experience with the very people they will be referring the families they work with through the practice with people and groups they have dealt with

personally. That personal experience creates very beneficial insight into not only what to ask for but also how to ask for it.

This model recognizes that understanding our emotional condition and being able to help others through the emotional process is the single most important part of the process. Dealing with our emotions in a healthy manner will allow us to build healthy relationships with the people who are trying to help us help our children. With this in mind, our partners receive training from Brad Thompson – a Licensed Professional Counselor/Supervisor – in understanding the emotional process. We also train them to be able to discern where another parent might be in that process, and what we might be able to do to help them, regardless of stage/place they might be in the process. After the initial training, we follow up with the partners on a monthly basis to monitor their emotional well-being and to help them through situations they are encountering in their practice. Mr. Thompson is also available to them on an individual basis as needed.

The skill training is broken down into the following pieces:

1. Rules of the Game, which include:
 - a. Families know best, but we don't know everything. Understanding the two ideas in this statement produce the courage to share their unique perspective and the humility to listen to others with a different perspective.
 - b. It will require skill to become effective advocates.
 - i. Martin Luther King said, "Things that are fought for and taken are often taken back. Things that are mutually agreed upon tend to last."
 - c. We must take care of ourselves.
 - d. We must nurture a sense of humor.
2. The Grief Process and Its Chronic Nature for Our Families:
 - a. Understanding the emotions and identifying where we are
 - b. The impact of transitions on our emotions
 - c. Stages of adaptation – surviving, searching, and settling in
 - d. The Psychology of Resilience
3. Creating a Balanced Lifestyle
4. The Importance of Having an Appropriate Dream
5. Developing a Master Plan for Your Family
6. Having Hard Conversations
 - a. Why important conversations are so hard to have
 - b. Questions we need to answer before having a hard conversation
 - c. Choosing not to play the blame game.
 - d. Lessons from "The Box"

7. Awareness of Community Resources
8. Developing/Recognizing Shared Purpose
9. Creating a "wrap-around" service plan that addresses as many of the individual's and family's needs as possible, medical and otherwise.

This model supports and enhances many of the components of the medical home – which is included in all federal healthcare legislation as well as best practice literature published by the American Academy of Pediatrics and the American Academy of Family Physicians. For more information about the Medical Home, please see the attached article at the end of this proposal. Some of the elements that this project influences are:

1. **Comprehensive care** – the parent partner bridges the gap between the medical practice and other areas of concern for the parent – education, social services, family issues, etc.
2. **Family-centered care.** Seems fairly obvious.
3. **Coordinated care** – in the medical home model, this component has more to do with coordinating medical care among subspecialists. But well-trained family members are the best resources for helping parents balance all of their responsibilities and maintain a healthy balance in life.
4. **Compassionate** – while I believe it is important for the doctor to take some time to provide this element, if the practice has someone who actually walks this path in an emotionally healthy way to refer the family to, the doctor can operate more efficiently and the parent/patient can receive more attention.
5. **Culturally effective** – having teams can allow us to possibly even match families of similar cultures. If that is not possible, we can at least train parents to be culturally sensitive (the advantage of doing local training) while maintaining the peer connection (of being parents).

Providing these medical home components more efficiently and effectively will address the dissatisfaction of parents with the current system. Based on information gathered by the Boys Town Institute for Child Health Improvement, parents expressed frustration at focus being placed solely on the acute health needs of the child while often failing to see the larger picture of the child being a part of a family and even a community. Because of this, the child usually receives the necessary medical treatment, but the larger needs of the family often go unattended. The survey reported a high level of stress associated with a child with special needs, and a disconnection with resources available in the community. Physicians reported similar frustration. They recognize the unmet needs but feel unequipped to meet those needs for families.

Benefits To The Medical Community

Our model increases the likelihood of someone in the practice being able to follow up with families concerning their issues and the challenges they experience as a result of those issues. The development of this relationship increases the likelihood of care plan follow-through as well as the discovery of barriers to executing that plan. I've included slides of findings from two different studies that reflect the benefit of high quality medical homes to the healthcare system. The studies reflect the following improvements in care:

1. Reduction of appointment no-shows
2. Reduction of emergency room visits
3. Reduction of hospital readmissions
4. Increased practice efficiency
5. Increased patient/family satisfaction